Original article
doi:10.1111/codi.15357

# Subjective expectations regarding longevity and future health: a cross-sectional survey among patients with Crohn's disease

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Received 6 July 2020; accepted 31 August 2020; Accepted Article online 13 September 2020

## Abstract

**Aim** The aim was to explore the subjective health expectations (sHE) of patients with Crohn's disease (CD) for both the near future and the elderly.

**Method** A cross-sectional survey was performed in four gastroenterology centres in Hungary. Consecutive outpatients with CD with age ≥ 18 were recruited. Socio-demographic and disease characteristics were recorded and the Crohn's Disease Activity Index (CDAI), Perianal Disease Activity Index, Patients' Global Assessment (PGA) and current pain visual analogue scale (VAS) were assessed. Subjective life expectancy (sLE) was explored and compared to statistical life expectancy. Current health and sHE for 1 year ahead and for ages 60/70/80/90 were assessed using the descriptive system of the EQ-5D-3L.

**Results** In all, 206 patients (54.9% men) with a mean age of 34.7 (SD 10.5 years) and disease duration of 10.5 (SD 6.3) years were studied. The CDAI score was 110.5 (SD 77.0) and 66% were treated by biologic drugs. Mean current EQ-5D-3L score was 0.80 (SD 0.17) and patients expected a 0.05 (SD 0.15) improvement within a year ($P < 0.05$). For ages 60/70/80/90, a mean EQ-5D-3L score of 0.59, 0.38, 0.10 and −0.12 respectively was provisioned. Age, current health status, sLE, PGA and pain VAS showed significant correlation with both 1-year and older age sHE ($P < 0.05$). Long-term sHE and sLE were negatively affected by the presence of extraintestinal manifestations but not by previous CD-related surgery.

**Conclusion** Patients with CD expect severe deterioration in health in later life. Given that unrealistic sHE may affect patients' current quality of life and health behaviour, we encourage physicians to explore and consider CD patients' sHE in clinical care.

**Keywords** Crohn's disease, expectations, life expectancy, quality of life, EQ-5D-3L

**What does this paper add to the literature?**

- Thisis the first study to explore subjective health expectations of patients with Crohn's disease.
- Patientsexpect significant improvement in their health within a year but severe deterioration in later life.
- Discussionsbetween patients and gastroenterologists about evidence-based health expectations deserve more attention in Crohn's disease care.

## Introduction

Crohn's disease (CD) is a chronic inflammatory bowel disease that may affect any part of the digestive track causing abdominal pain and diarrhoea, and may lead to functional disability and to life-threatening complications. Living with CD may cause a substantial burden on patients due to alterations in their current health, but not less importantly due to concerns and uncertainties they may have regarding their future health [1]. Patients' preferences and expectations regarding treatments and healthcare have come into focus in the past years [2–4]. However, still little is known about how conscious CD patients are about the chronicity and course of their disease and its impact on their future

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health, yet these can play a key role in their current lifestyle and health-related decisions [5,6].

Brouwer and colleagues highlighted that individuals' subjective health expectations (sHE) may differ from objective measures and inaccurate subjective expectations regarding length and quality of life may have important implications for health behaviour [7–9]. Those who underestimate their future health may place less importance on seeking medical care and be less compliant. In contrast, overestimation of future health can influence negatively the perception of actual treatment effects and may lead to dissatisfaction with care. These issues are especially relevant and can be deterministic for successful care in chronic diseases, such as CD, that require long-term care and compliance.

The aim of our study was therefore to explore CD patients' sHE regarding their health status 1 year ahead and for ages 60, 70, 80 and 90, as well as their beliefs on longevity. Secondarily, we aimed to analyse determinants of sHE and compare CD patients' results with previous studies among the general public and other chronic diseases.

## Method

### Study design

A cross-sectional survey was conducted at three academic gastroenterology departments and an inflammatory bowel diseases centre in Hungary. Details of the study have been described elsewhere [10,11]. In brief, consecutive outpatients aged 18 years and over, with a definitive diagnosis of CD, were invited to participate in the study. Ethical approval for conducting the study was granted by the National Scientific and Ethical Committee (reference no. 49548-4/2016/EKU) and the study was performed in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki and its later amendments or comparable ethical standards. Informed consent was signed by all patients. A paper-based questionnaire survey was performed in which patients were asked about their socio-demographic characteristics (self-reported sex, date of birth, educational level, residence, employment status), CD-related symptoms and health status. Gastroenterologists provided data on patients' medical history, clinical characteristics, disease severity and treatments.

### Measurement tools

*Crohn's Disease Activity Index (CDAI)*

CDAI is a measure of disease activity in CD [12]. It includes signs and symptoms based on the past 7 days, and consists of eight components with a weight factor attached to each. The total score is calculated by the physician as a sum of items multiplied by weighting factors. Cut-offs for remission or low disease activity, mildly active, moderately active and severely active disease are < 150, 150–219, 220–449 and 450–600, respectively [13].

*Perianal Disease Activity Index (PDAI)*

The PDAI measures the severity of perianal fistulising CD, covering five dimensions: fistula discharge, pain and restriction of activities, sexual activity restriction, type of perianal disease, and degree of induration [14]. Each dimension is scored on a scale between 0 (no symptoms) and 4 (severe symptoms); the total PDAI score is calculated as the sum of the items (range between 0 and 20). PDAI ≤ 4 indicates inactive disease while PDAI > 4 is considered as active disease [15].

*Visual analogue scale (VAS)*

The Patients' Global Assessment VAS (PGA VAS) of 0–100 with end-points defined as 'not severe at all' (0) and 'very severe' (100) was applied to assess patients' self-perceived severity of CD in general. CD-related current pain and the worst experienced CD-related pain in the past 3 months were measured separately with a 0–100 VAS (pain VAS and worst pain VAS, respectively), with end-points of 'no pain at all' (score 0) and 'pain as bad as it could be' (score 100).

*EQ-5D-3L questionnaire*

The EQ-5D-3L is a generic health status measure consisting of two parts [16,17]. The first part is a descriptive system covering five dimensions of health: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Respondents are asked to indicate on a three-level response scale (1 – no problem; 2 – some/moderate problem; 3 – unable/extreme problem) for each dimension that best describes their current health status. Preference weight (utility) originating from population-based studies can be attached to each health state description. Due to lack of country-specific tariffs in Hungary, the value set of the UK by Dolan was used (score range from −0.549 to 1.0) [18]. The second part is a vertical 20 cm visual analogue scale (EQ VAS) with end-points of 0 indicating the worst imaginable health status and 100 indicating the best imaginable health status.

### Assessment of subjective expectations on future health and longevity

Patients were asked to indicate on the descriptive system of the EQ-5D-3L questionnaire the health status they

 

expect to have a year later. To assess sHE for future ages, we followed the same methodology that has been successfully used in previous studies [7,8,19–22] (Table S1). Patients were asked to indicate the level of health problems they think they will have at ages 60, 70, 80 and 90 in the five dimensions of the EQ-5D-3L. The EQ-5D-3L index scores for the subjectively expected health states were calculated. Patients were also asked to indicate the age to which they expected to live (subjective life expectancy, sLE).

### Statistical analysis

The difference between patients' sLE and age- and sex-matched statistical life expectancy was computed based on data retrieved from the Hungarian Central Statistical Office (latest available data: year 2016) [23]. The differences between expected (at year 1) and current EQ-5D-3L index scores and between patients' subjective and statistical life expectancy were tested by Wilcoxon signed-rank test. sHE across subgroups of patients were compared by using the Mann–Whitney $U$ test or Kruskal–Wallis test, as appropriate. The relationship between the continuous variables was analysed by Spearman's correlations. A correlation coefficient of 0–0.19 was defined as very weak, 0.20–0.39 as weak, 0.40–0.59 as moderate, 0.60–0.79 as strong and 0.80–1 as a very strong correlation. All the applied statistics were two-sided with a significance level of $P < 0.05$. Statistical analyses were performed with IBM SPSS version 25.0 (SPSS Inc., Chicago, Illinois, USA).

## Results

Two hundred and six patients (54.9% men) with a mean age of 34.7 (SD 10.5, range 18–70, median 34) years participated in the survey. There were 31 patients in the age group 45–54, but only seven patients in age group 55–64 and one aged over 65; therefore we joined these three age groups for the analyses. Main clinical and socio-demographic characteristics of the sample are presented in Table 1. The average disease duration was 10.5 (SD 6.3; $N = 205$) years, the mean CDAI score was 110.5 (SD 77.0; $N = 206$) and the PDAI score was 3.7 (SD 2.3; $N = 83$). The PGA, current and worst pain in the past 3 months VAS scores were on average 50.1 (SD 23.9; $N = 204$), 24.7 (SD 23.9; $N = 206$) and 42.0 (SD 31.4; $N = 206$), respectively. The majority (75.7%) of the patients had low disease activity or were in remission (CDAI < 150) and 66.0% were treated with a biologic drug at the time of the assessment: infliximab 46.6%, adalimumab 17.5%, vedolizumab 1.9%. Current general health status as measured by the EQ-5D-3L index was on average 0.8 (SD 0.17; $N = 203$) and 72.7 (SD 19.7) on the EQ VAS.

### Patients' subjective health expectations for 1 year ahead and for ages 60, 70, 80 and 90

Patients expected a modest improvement (mean 0.05, SD 0.15, $P < 0.05$) in their health within a year on the EQ-5D-3L index (Table 1). Women expected somewhat greater improvement than men but the provisioned change was statistically significant in both subgroups. The highest difference between the current and expected EQ-5D-3L index score was observed in age group 18–24 years.

Patients expected a significant worsening of their health status with age achieving a mean score of −0.12 (SD 0.52) at age 90 (Table 1). The expected health status for older ages did not differ significantly by sex, educational level, clinical subtype (fistula), present treatment type or by having had or not CD-related surgery in the past. In contrast, the difference was statistically significant across age groups for all the four future ages. Those who had had extraintestinal manifestation expected significantly worse health status for ages 60 and 70. We did not find a significant difference between subgroups who expected or not to reach the specific future ages in question.

### Patients' subjective expectations for longevity

The main findings are presented in Table 2. Patients with CD expected to live up to 76.8 (SD 3.5; range 40–100) years of age on average. Women and patients in age group 35–44 expected on average 3.0 (SD 12.0) and 4.2 (SD 10.6) years shorter life than their sex- and age-matched statistical life expectancy, respectively. Significant but weak negative correlations were found between sLE and current general health and pain (EQ-5D-3L, PGA VAS, pain VAS), but not with the disease-specific CDAI and PDAI scores. Correlations between sLE and sHE for 1-year ahead and for future ages were weak and moderate, respectively (Table 3).

### Correlations between subjective health expectations and patient characteristics

Results are presented in Table 3. With regard to sHE in 1 year's time, we found that patients who were younger, had shorter disease duration and better general health status (EQ-5D-3L) expected to have a significantly better EQ-5D-3L index score. Stronger CD-related pain (currently and in the past 3 months) negatively influenced the expected EQ-5D-3L score for

 

**Table 1** Patients' actual health-related quality of life and subjective expectations for the future (mean, SD)

| | | | | | Difference between expected (at year 1) and current EQ-5D-3L index scores | Expected EQ-5D-3L index scores at age | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | *N* (%) | Current EQ-5D-3L index score | Expected EQ-5D-3L index score for 1 year ahead | | 60 years | 70 years | 80 years | 90 years |
| | *N* (response rate, %) | | 203 (98.5) | 202 (98.1) | 199 (96.6) | 193 (93.7) | 193 (93.7) | 185 (89.8) | 180 (87.4) |
| | Total sample | 206 | 0.80 (0.17) | 0.85 (0.17) | 0.05 (0.15)* | 0.59 (0.40) | 0.38 (0.49) | 0.10 (0.53) | –0.12 (0.52) |
| Sex | Female | 93 (45.1) | 0.79 (0.17) | 0.84 (0.19) | 0.06 (0.17)* | 0.63 (0.39) | 0.42 (0.49) | 0.12 (0.55) | –0.10 (0.54) |
| | Male | 113 (54.9) | 0.81 (0.17) | 0.86 (0.15) | 0.04 (0.14)* | 0.56 (0.41) | 0.34 (0.5) | 0.08 (0.51) | –0.13 (0.51) |
| Age groups | 18–24 | 37 (18) | 0.83 (0.16) | 0.94 (0.11)† | 0.11 (0.13)* | 0.76 (0.26)† | 0.61 (0.39)† | 0.38 (0.42)† | 0.18 (0.5)† |
| | 25–34 | 71 (34.5) | 0.82 (0.17) | 0.9 (0.13)† | 0.08 (0.15)* | 0.59 (0.4)† | 0.38 (0.47)† | 0.03 (0.53)† | –0.18 (0.49)† |
| | 35–44 | 59 (28.6) | 0.77 (0.19) | 0.81 (0.19)† | 0.04 (0.17) | 0.46 (0.48)† | 0.27 (0.53)† | –0.10 (0.57)† | –0.18 (0.56)† |
| | 45– | 39 (18.9) | 0.78 (0.15) | 0.75 (0.19)† | –0.03 (0.12) | 0.66 (0.37)† | 0.31 (0.52)† | 0.12 (0.48)† | –0.21 (0.44)† |
| Education (missing $n = 1$) | Lower | 14 (6.8) | 0.72 (0.18) | 0.77 (0.14)† | 0.04 (0.14) | 0.58 (0.51) | 0.47 (0.43) | 0.08 (0.53) | –0.24 (0.47) |
| | Secondary | 132 (64.4) | 0.80 (0.18) | 0.84 (0.18)† | 0.04 (0.15)* | 0.58 (0.39) | 0.34 (0.52) | 0.10 (0.54) | –0.09 (0.53) |
| | College/ university | 59 (28.8) | 0.82 (0.16) | 0.89 (0.13)† | 0.08 (0.16)* | 0.63 (0.39) | 0.46 (0.44) | 0.10 (0.51) | –0.13 (0.51) |
| Fistula‡ | No | 122 (59.2) | 0.79 (0.17) | 0.86 (0.15) | 0.07 (0.15)* | 0.55 (0.44) | 0.35 (0.51) | 0.06 (0.54) | –0.15 (0.52) |
| | Yes | 84 (40.8) | 0.81 (0.17) | 0.85 (0.19) | 0.03 (0.15)* | 0.66 (0.33) | 0.42 (0.47) | 0.15 (0.51) | –0.07 (0.51) |
| Extraintestinal manifestations‡ (missing $n = 1$) | No | 79 (38.5) | 0.85 (0.14)† | 0.91 (0.13) | 0.05 (0.11)* | 0.69 (0.35)† | 0.47 (0.46)† | 0.19 (0.51) | –0.05 (0.52) |
| | Yes | 126 (61.5) | 0.76 (0.18)† | 0.82 (0.18)† | 0.05 (0.17)* | 0.54 (0.43)† | 0.32 (0.53)† | 0.04 (0.53) | –0.16 (0.51) |
| Previous surgery | None | 87 (42.2) | 0.81 (0.17) | 0.86 (0.17) | 0.05 (0.16)* | 0.63 (0.37) | 0.36 (0.49) | 0.09 (0.5) | –0.12 (0.49) |
| | Resection | 33 (16) | 0.82 (0.18) | 0.83 (0.2) | 0.01 (0.1) | 0.62 (0.41) | 0.48 (0.49) | 0.18 (0.53) | –0.15 (0.53) |
| | Non-resection | 53 (25.7) | 0.80 (0.17) | 0.86 (0.16) | 0.07 (0.14)* | 0.58 (0.42) | 0.37 (0.5) | 0.08 (0.57) | –0.10 (0.57) |
| | Both | 33 (16) | 0.76 (0.18) | 0.84 (0.13) | 0.07 (0.18)* | 0.5 (0.47) | 0.32 (0.5) | 0.05 (0.56) | –0.12 (0.55) |
| Present treatment§ | Systemic non-biologic | 67 (32.5) | 0.76 (0.19) | 0.84 (0.17) | 0.08 (0.19)* | 0.60 (0.41) | 0.42 (0.47) | 0.13 (0.51) | –0.11 (0.48) |
| | Biologic | 136 (66.0) | 0.82 (0.16) | 0.86 (0.17) | 0.04 (0.13)* | 0.59 (0.41) | 0.36 (0.51) | 0.08 (0.54) | –0.12 (0.54) |
| Expected survivors¶ | Expected survivors | N/A | N/A | N/A | N/A | 0.62 (0.38) | 0.51 (0.41) | 0.34 (0.48) | 0.45 (0.38) |
| | Expected non-survivors | N/A | N/A | N/A | N/A | 0.00 (0.57) | 0.01 (0.54) | –0.1 (0.48) | –0.23 (0.47) |

In age group 45–54, mean (SD) EQ-5D-3L scores were currently 0.77 (0.14); expected for 1 year ahead 0.74 (0.19); for age 60, 0.63 (0.40); for age 70, 0.27 (0.51); for age 80, 0.08 (0.47); for age 90, −0.22 (0.44).

*Wilcoxon signed-rank test $P < 0.05$.

†Mann–Whitney $U$ test or Kruskal–Wallis test $P < 0.05$.

‡Symptom occurred either in the patient's history or was present at the time of the survey.

§There were three patients who did not get any treatment.

¶Expected to live until the future age asked.

1 year ahead. (Correlations were moderate or weak.) The relationship was not significant with either the CDAI or the PDAI scores. Our findings with respect to sHE at ages 60, 70, 80 and 90 were very similar, with a few exceptions (Table 3).

## Discussion and conclusions

In this empirical study we surveyed the sHE of adult CD patients attending for outpatient care at gastroenterology departments. Patients' current general health status was somewhat worse than that of the general population in Hungary (mean EQ-5D-3L index score of 0.80 at a mean age of 34.7 years *vs* 0.86 in age group 35–44 years) [24]. Patients expected on average a statistically significant improvement in their general health status (0.05-point increase on the EQ-5D-3L) within a year. To the best of our knowledge, a minimum clinically important difference for the EQ-5D-3L index score has not been established in CD, yet [25]. Nonetheless, we think this result indicates that patients expect rather a stability (non-worsening) and maybe some improvement of their disease in the near future.

 

**Table 2** Subjective and age- and sex-matched statistical life expectancy

| Variables | Subgroups | *N* (%) | Statistical life expectancy (years), *N* = 206 | Subjective life expectancy (years), *N* = 194 | Difference between statistical and subjective life expectancy (years), *N* = 194 | Wilcoxon signed-rank test *P* |
|---|---|---|---|---|---|---|
| Total sample | – | 206 | 76.8 (3.5) | 75.9 (11.5) | 0.95 (11.6) | 0.2174 |
| Sex | Female | 93 (45.1) | 80.5 (1.1) | 77.4 (12.0) | 3.0 (12.0)* | 0.0153 |
| | Male | 113 (54.9) | 73.7 (0.7) | 74.6 (11.1) | −0.9 (11.1) | 0.7063 |
| Age groups | 18–24 | 37 (18) | 76.6 (3.6) | 78.0 (12.1) | −1.3 (11.9) | 0.4559 |
| | 25–34 | 71 (34.5) | 75.7 (3.2) | 75.2 (11.9) | 0.5 (12.3) | 0.9033 |
| | 35–44 | 59 (28.6) | 77.3 (3.4) | 73.1 (10.6) | 4.2 (10.6)* | 0.0037 |
| | 45– | 39 (18.9) | 78.2 (3.7) | 79.9 (10.5) | −1.3 (11.1) | 0.7934 |
| Education (missing *n* = 1) | Lower | 14 (6.8) | 76.3 (3.5) | 72.6 (13.5) | 3.9 (12.2) | 0.4628 |
| | Secondary | 132 (64.4) | 76.8 (3.5) | 75.6 (11.6) | 1.3 (11.9) | 0.1709 |
| | College/university | 59 (28.8) | 77.0 (3.6) | 77.7 (10.7) | −0.7 (10.9) | 0.7145 |
| Fistula | No | 122 (59.2) | 76.5 (3.4) | 74.8 (11.5) | 1.8 (11.5) | 0.1054 |
| | Yes | 84 (40.8) | 77.1 (3.6) | 77.7 (11.4) | −0.4 (11.8) | 0.9794 |
| Extraintestinal manifestations | No | 149 (72.3) | 76.5 (3.5) | 76.8 (11.9) | −0.2 (12.0) | 0.8850 |
| | Yes | 57 (27.7) | 77.4 (3.5) | 73.5 (10.1) | 4.2 (9.9)* | 0.0069 |
| Previous surgeries | None | 87 (42.2) | 76.8 (3.5) | 78.0 (11.7) | −1.1 (12.1) | 0.5707 |
| | Resection | 33 (16) | 77.2 (3.8) | 77.3 (10.7) | −0.1 (10.5) | 0.7761 |
| | Non-resection | 53 (25.7) | 76.4 (3.5) | 73.7 (11.0) | 2.8 (10.8) | 0.0504 |
| | Both | 33 (16) | 76.9 (3.3) | 72.6 (11.9) | 4.3 (12.2) | 0.0649 |
| Present treatment | None | 3 (1.5) | 78.3 (3.8) | 70.0 (13.2) | 8.3 (13.0) | 0.2851 |
| | Systemic non-biologic | 67 (32.5) | 76.6 (3.5) | 75.7 (10.2) | 1.2 (11.3) | 0.5432 |
| | Biologic | 136 (66) | 76.8 (3.5) | 76.2 (12.1) | 0.7 (11.8) | 0.4139 |
| Disease activity groups | CDAI < 150 | 156 (75.7) | 76.72 (3.54) | 76.12 (11.37) | 0.69 (11.43) | 0.2817 |
| | CDAI 150–219 | 32 (15.5) | 76.03 (3.38) | 77.45 (10.57) | −1.14 (10.11) | 0.5240 |
| | CDAI 220 ≥ | 18 (8.7) | 78.50 (2.81) | 72.06 (13.92) | 6.44 (14.37) | 0.109 |
| Retired due to Crohn's disease | Yes | 47 (22.8) | 77.60 (3.48) | 72.41 (11.46) | 5.27 (11.24) | 0.0061 |
| | No | 159 (77.2) | 76.52 (3.47) | 76.97 (11.36) | −0.31 (11.48) | 0.9575 |
| Stoma | Yes | 10 (4.9) | 76.30 (3.43) | 72.10 (9.46) | 4.20 (10.56) | 0.3270 |
| | No | 196 (95.1) | 76.79 (3.50) | 76.15 (11.60) | 0.78 (11.69) | 0.3271 |

*$P < 0.05$.

In contrast, CD patients provisioned a sharp deterioration of health in their older age (Table 1). CD patients expected to have worse health status than the general population at these ages (Fig. 1). The gap between short-term and long-term sHE suggests that CD patients attending gastroenterology care are rather optimistic regarding their health in the immediate future but they have serious concerns about their chances to have well-controlled disease over a lifetime. Qualitative studies are suggested to explore the underlying causes, including medical, social (access, affordability) and patient-related reasons [26,27]. Clinicians should make efforts to explore patients' sHE and help them to put their sHE on a realistic perspective based on the available evidence. On the one hand, overestimation of short-term treatment effects may lead to disappointments regarding the results achieved and may induce feelings of inadequacy and lead to worsening of compliance. On the other hand, a pessimistic vision about the distant future is probably an unfounded extra burden and avoidable harm on most CD patients.

Our analyses revealed that age, disease duration, self-reported current health (EQ-5D-3L) and pain measures correlated significantly with 1-year sHE but disease activity measures (CDAI, PDAI) did not (Table 3). Current health correlated significantly also with sHE for ages 60, 70 and 80. Hence applying these patient-reported outcomes alongside the standard medical decision making tools (CDAI and PDAI) is strongly suggested as these carry valuable information not only about patients' current self-perceived status but also about their beliefs on health perspectives.

 

**Table 3** Spearman's correlations between subjective health expectations and continuous variables

| | Expected EQ-5D-3L index score in 1 year | | Expected EQ-5D-3L index score at the age of . . . | | | | Expected length of life | |
|---|---|---|---|---|---|---|---|---|
| Variables | EQ-5D-3L index score in 1 year | Difference expected (in 1 year) – current | 60 years | 70 years | 80 years | 90 years | Subjective LE | Difference statistical – subjective LE |
| Age (years) | −0.421* | −0.341* | −0.17 | −0.267* | −0.191* | −0.231* | −0.039 | 0.137 |
| Disease duration (years) | −0.198* | −0.201* | −0.127 | −0.162* | −0.14 | −0.129 | −0.09 | 0.135 |
| EQ-5D-3L (−0.549–1) | 0.664* | −0.289* | 0.572* | 0.504* | 0.424* | 0.292* | 0.307* | −0.333* |
| EQ VAS (0–100) | 0.428* | −0.135 | 0.333* | 0.354* | 0.326* | 0.238* | 0.23* | −0.252* |
| CDAI (0–600) | −0.049 | 0.139* | −0.029 | −0.116 | −0.103 | −0.038 | 0.02 | 0.004 |
| PDAI (0–20) | −0.066 | 0.137 | 0.039 | 0.175 | 0.088 | 0.154 | 0.21 | −0.14 |
| Patient's Global Assessment VAS (0–100) | −0.305* | 0.067 | −0.280* | −0.259* | −0.257* | −0.173* | −0.143* | 0.163* |
| Current pain VAS (0–100) | −0.376* | 0.137 | −0.297* | −0.188* | −0.151* | −0.073 | −0.170* | 0.236* |
| Worst pain VAS in the past 3 months (0–100) | −0.300* | 0.188* | −0.255* | −0.174* | −0.183* | −0.79 | −0.180* | 0.235* |
| Subjective life expectancy (years) | 0.242* | −0.049 | 0.592* | 0.523* | 0.535* | 0.519* | – | -0.941* |
| Statistical life expectancy (years) | −0.185* | −0.092 | 0.019 | −0.041 | −0.031 | −0.082 | 0.099 | 0.208* |

CDAI, Crohn's Disease Activity Index; EQ VAS, is a vertical 20 cm visual analogue scale with endpoints of 0 indicating the worst imaginable health state and 100 indicating the best imaginable health state; LE, life expectancy; PDAI, Perianal Disease Activity Index; VAS, visual analogue scale.
*Spearman's rho $P < 0.05$.

Most of the patients did not expect significant shortening of their life due to CD although an increased standardized mortality ratio may occur, especially in specific subgroups with CD [28]. sLE showed significant correlations with sHE. Therefore, it is strongly suggested to explore these two in parallel.

Comparisons with some previous studies deserve mentioning. sHE for future ages were explored in two online surveys among the general population in Hungary [19,29]. Both confirmed that people in general expect health deterioration with age and the expected health status is worse than the actual health status of the general public from age 70 and above. The same pattern was observed among the general population in the Netherlands [7]. Two separate studies in Hungary involving patients with rheumatoid arthritis and psoriasis reported very similar findings to ours in CD [20,21] (Fig. 1). It seems that, despite the incredible development that health professionals have witnessed in the past two decades in the treatment of inflammatory diseases in rheumatology, dermatology and gastroenterology, many patients still have little confidence in having good health in old age. Another similarity is that rheumatoid arthritis patients expected a robust improvement in health in the short term at the initiation of their first biologic treatment. Nonetheless, it was proved to be an overestimation based on the measurements at the follow-up visit [20]. Hence we think that more attention should be paid to informing patients about the awaited size, timing and character of the treatment effects, as well as about long-term effects of adequate care. To the best of our knowledge, similar studies have not been performed for inflammatory bowel disease patients.

Some limitations of our study deserve mentioning and we would like to suggest a few directions for further research. Patients in remission and with mildly active disease were overrepresented in the sample while only few patients aged 55 and over participated in the study. Given the cross-sectional design we could not match sHE to measured data. Therefore, we suggest testing the results of this explorative research in larger prospective studies involving representative patient samples and analysing the determinants of sHE. It is recommended to record response rate (which we have omitted) in order to assess potential non-response bias.

 

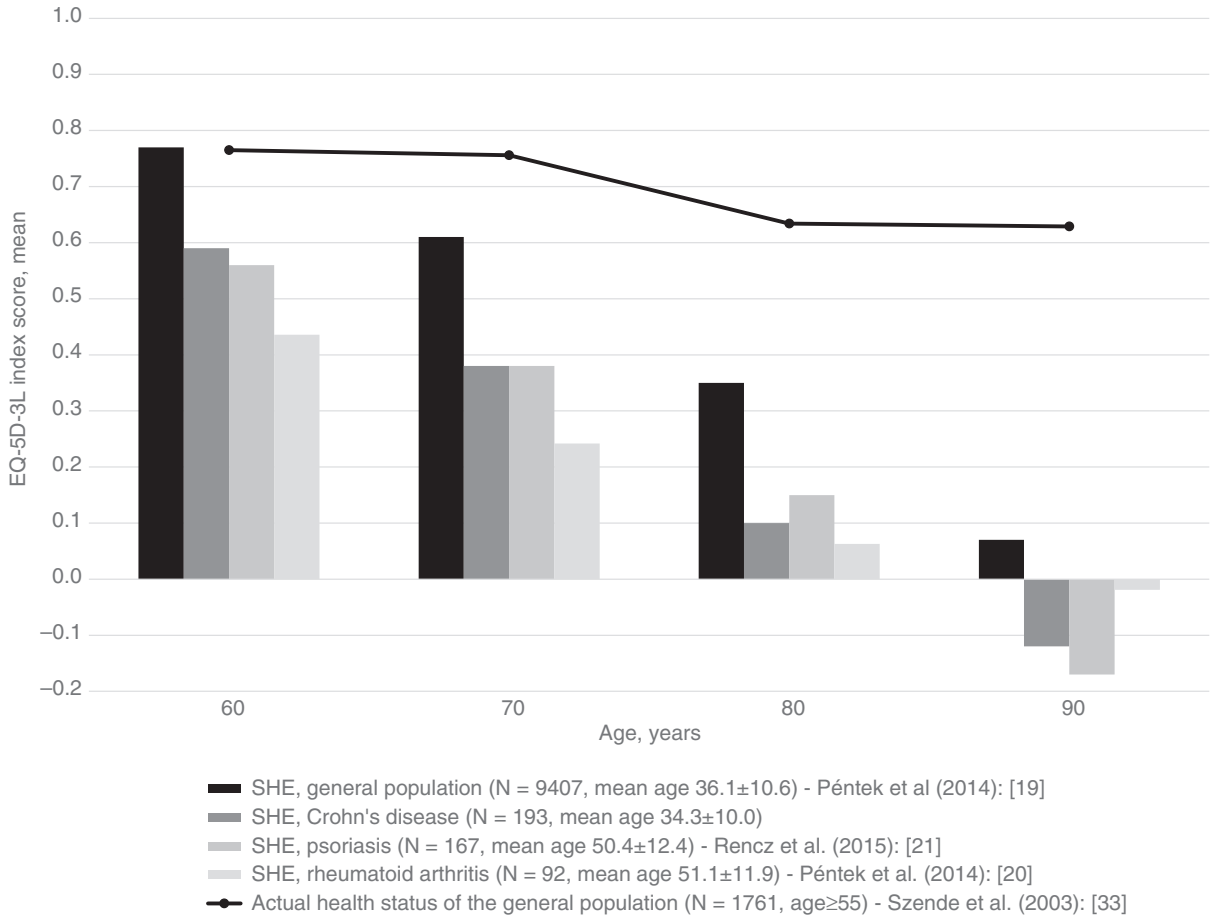


**Figure 1** CD patients' subjective health expectations (sHE) for future ages in comparison with sHE of the general population and other patient groups, as well as with the actual health status of the general population of Hungary.

We suggest considering the use of the EQ-5D-5L version (with five-level response scale) to explore sHE in future studies [30]. The EQ-5D-5L has been proved to have better measurement properties as a health status measure than the EQ-5D-3L [10], and we expect an increase in its use in CD registries and clinical studies. We used the tariffs of the UK to calculate actual and expected EQ-5D-3L scores due to lack of local tariffs at the time of the analyses. These tariffs may differ significantly across countries [31], and indeed, according to our preliminary analyses using the recently published country-specific tariffs for Hungary [32] we found somewhat different scores (slightly lower average score for current status and higher for 1 year ahead, and it was decreasing for future ages but at varying degrees; data not shown). For comparability reasons, we stayed with the UK value set in this current study. It would be useful also to investigate the potential disagreements between patients' and clinicians' views. Patients' sHE regarding treatment effects may change with the number of therapy failures and thus influence the evaluation of subsequent treatments. Influencing factors of sHE have only been partly identified in our study; further research (on health literacy, personality traits, cultural characteristics, availability of health and social care support) is recommended.

In conclusion, our study suggests that CD patients attending gastroenterology care expect health improvement in the near future but a severe health deterioration in later life. Patients' age, current general health status and pain seem to have a significant impact on sHE, but clinical history and current treatment might have substantial influence as well. We believe that our research has opened valuable new doors in the care of CD patients and hope it will inspire new sHE studies.

## Acknowledgements

The authors are grateful to Drs László Dávida, Lóránt Gönczi, Zsuzsanna Kürti, Szilvia Lovas, Tamás Molnár,

 

Marianna Rutka Eszter Schäfer, Tamás Szamosi, Ferenc Zsigmond and Zsuzsanna Végh for their contribution to data collection. Special thanks to Tamás Cserni for converting the paper-based data into an electronic dataset and assisting with the data analyses.

## Conflicts of interest

Márta Péntek is member of the EuroQol Group, a not-for-profit organization that develops and distributes instruments that assess and value health. The other authors report no conflict of interest.

## Funding

This research got no funding.

## Ethics approval

Ethical approval for conducting the study was granted by the National Scientific and Ethical Committee of Hungary (reference no. 49548-4/2016/EKU). The study has been performed in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki and its later amendments or comparable ethical standards.

## Patient consent

An informed consent form was signed by all patients before the survey.

## Permission to reproduce material from other sources

Not applicable.

## Clinical trial registration

Not applicable.

## Data availability statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

## References

1 Garcia-Sanjuan S, Lillo-Crespo M, Richart-Martinez M, Sanjuan QA. Understanding life experiences of people affected by Crohn's disease in Spain. A phenomenological approach. *Scand J Caring Sci* 2018; **32:** 354–62.

2 Guarini A, Biagini S, Capaldi A *et al.* Satisfaction and expectations of patients with inflammatory bowel disease on biologic therapy: a multicenter study. *Ann Gastroenterol* 2017; **30:** 96–100.

3 Pittet V, Vaucher C, Froehlich F, Maillard MH, Michetti P, Swiss IBDCSG. Patient-reported healthcare expectations in inflammatory bowel diseases. *PLoS One* 2018; **13:** e0197351.

4 Casellas F, Herrera-de Guise C, Robles V, Navarro E, Borruel N. Patient preferences for inflammatory bowel disease treatment objectives. *Dig Liver Dis* 2017; **49:** 152–6.

5 Catalan-Serra I, Huguet-Malaves JM, Minguez M *et al.* Information resources used by patients with inflammatory bowel disease: satisfaction, expectations and information gaps. *Gastroenterol Hepatol* 2015; **38:** 355–63.

6 Pittet V, Vaucher C, Maillard MH *et al.* Information needs and concerns of patients with inflammatory bowel disease: what can we learn from participants in a bilingual clinical cohort? *PLoS One* 2016; **11:** e0150620.

7 Brouwer WB, van Exel NJ. Expectations regarding length and health related quality of life: some empirical findings. *Soc Sci Med* 2005; **61:** 1083–94.

8 Rappange DR, Brouwer WB, van Exel J. A long life in good health: subjective expectations regarding length and future health-related quality of life. *Eur J Health Econ* 2016; **17:** 577–89.

9 Rappange DR, Brouwer WB, van Exel J. Rational expectations? An explorative study of subjective survival probabilities and lifestyle across Europe. *Health Expect.* 2016; **19:** 121–37.

10 Rencz F, Lakatos PL, Gulacsi L *et al.* Validity of the EQ-5D-5L and EQ-5D-3L in patients with Crohn's disease. *Qual Life Res* 2019; **28:** 141–52.

11 Rencz F, Stalmeier PFM, Pentek M *et al.* Patient and general population values for luminal and perianal fistulising Crohn's disease health states. *Eur J Health Econ* 2019; **20:** S91–S100.

12 Teixeira M, Ferguson A. Uses and limitations of the Crohn's disease activity index. *Arq Gastroenterol* 1979; **16:** 67–72.

13 Griffiths AM, Otley AR, Hyams J *et al.* A review of activity indices and end points for clinical trials in children with Crohn's disease. *Inflamm Bowel Dis* 2005; **11:** 185–96.

14 Irvine EJ. Usual therapy improves perianal Crohn's disease as measured by a new disease activity index. McMaster IBD Study Group. *J Clin Gastroenterol* 1995; **20:** 27–32.

15 Losco A, Vigano C, Conte D, Cesana BM, Basilisco G. Assessing the activity of perianal Crohn's disease: comparison of clinical indices and computer-assisted anal ultrasound. *Inflamm Bowel Dis* 2009; **15:** 742–9.

16 EuroQol G. EuroQol – a new facility for the measurement of health-related quality of life. *Health Policy* 1990; **16:** 199–208.

17 Rencz F, Gulacsi L, Drummond M *et al.* EQ-5D in central and Eastern Europe: 2000–2015. *Qual Life Res* 2016; **25:** 2693–710.

 

18 Dolan P. Modeling valuations for EuroQol health states. *Med Care* 1997; **35:** 1095–108.
19 Pentek M, Brodszky V, Gulacsi AL *et al.* Subjective expectations regarding length and health-related quality of life in Hungary: results from an empirical investigation. *Health Expect* 2014; **17:** 696–709.
20 Pentek M, Gulacsi L, Rojkovich B, Brodszky V, van Exel J, Brouwer WB. Subjective health expectations at biological therapy initiation: a survey of rheumatoid arthritis patients and rheumatologists. *Eur J Health Econ* 2014; **15:** S83–92.
21 Rencz F, Hollo P, Karpati S *et al.* Moderate to severe psoriasis patients' subjective future expectations regarding health-related quality of life and longevity. *J Eur Acad Dermatol Venereol* 2015; **29:** 1398–405.
22 Pentek M, Brodszky V, Biro Z *et al.* Subjective health expectations of patients with age-related macular degeneration treated with antiVEGF drugs. *BMC Geriatr* 2017; **17:** 233.
23 Office HCS. 2016 http://www.ksh.hu/?lang=en (accessed 11 November 2019).
24 Baji P, Brodszky V, Rencz F, Boncz I, Gulacsi L, Pentek M. Health status of the Hungarian population between 2000–2010. *Orv Hetil* 2015; **156:** 2035–44.
25 Coretti S, Ruggeri M, McNamee P. The minimum clinically important difference for EQ-5D index: a critical review. *Expert Rev Pharmacoecon Outcomes Res* 2014; **14:** 221–33.
26 Fidder HH, Singendonk MM, van der Have M, Oldenburg B, van Oijen MG. Low rates of adherence for tumor necrosis factor-alpha inhibitors in Crohn's disease and rheumatoid arthritis: results of a systematic review. *World J Gastroenterol* 2013; **19(27):** 4344–50.
27 Boncz I, Sebestyen A. Financial deficits in the health services of the UK and Hungary. *Lancet* 2006; **368:** 917–8.
28 Selinger CP, Leong RW. Mortality from inflammatory bowel diseases. *Inflamm Bowel Dis* 2012; **18:** 1566–72.
29 Pentek M, Hajdu O, Rencz F *et al.* Subjective expectations regarding ageing: a cross-sectional online population survey in Hungary. *Eur J Health Econ* 2019; **20:** S17–S30.
30 Herdman M, Gudex C, Lloyd A *et al.* Development and preliminary testing of the new five-level version of EQ-5D (EQ-5D-5L). *Qual Life Res* 2011; **20:** 1727–36 .31.
31 Janssen MF, Szende A, Cabases J *et al.* Population norms for the EQ-5D-3L: a cross-country analysis of population surveys for 20 countries. *Eur J Health Econ* 2019; **20:** 205–16.
32 Rencz F, Brodszy V, Gulácsi L *et al.* Parallel valuation of the EQ-5D-3L and EQ-5D-5L by time trade-off in Hungary. *Value Health* 2020; **23:** 1235–45.
33 Szende A, Renáta Németh R. Health-related quality of life of the Hungarian population. *Orv Hetil* 2003; **144:** 1667–74.

## Supporting Information

Additional Supporting Information may be found in the online version of this article:

**Table S1.** Questions used to explore subjective health expectations for future ages.

 